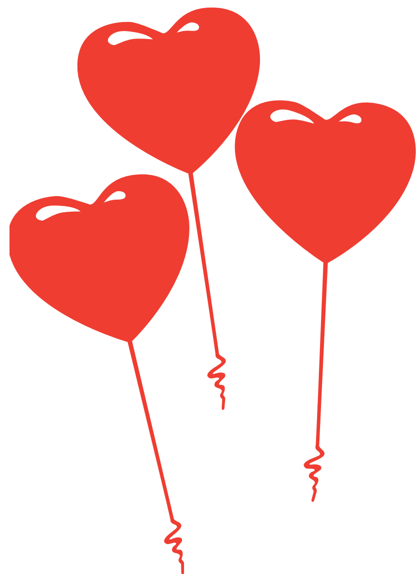
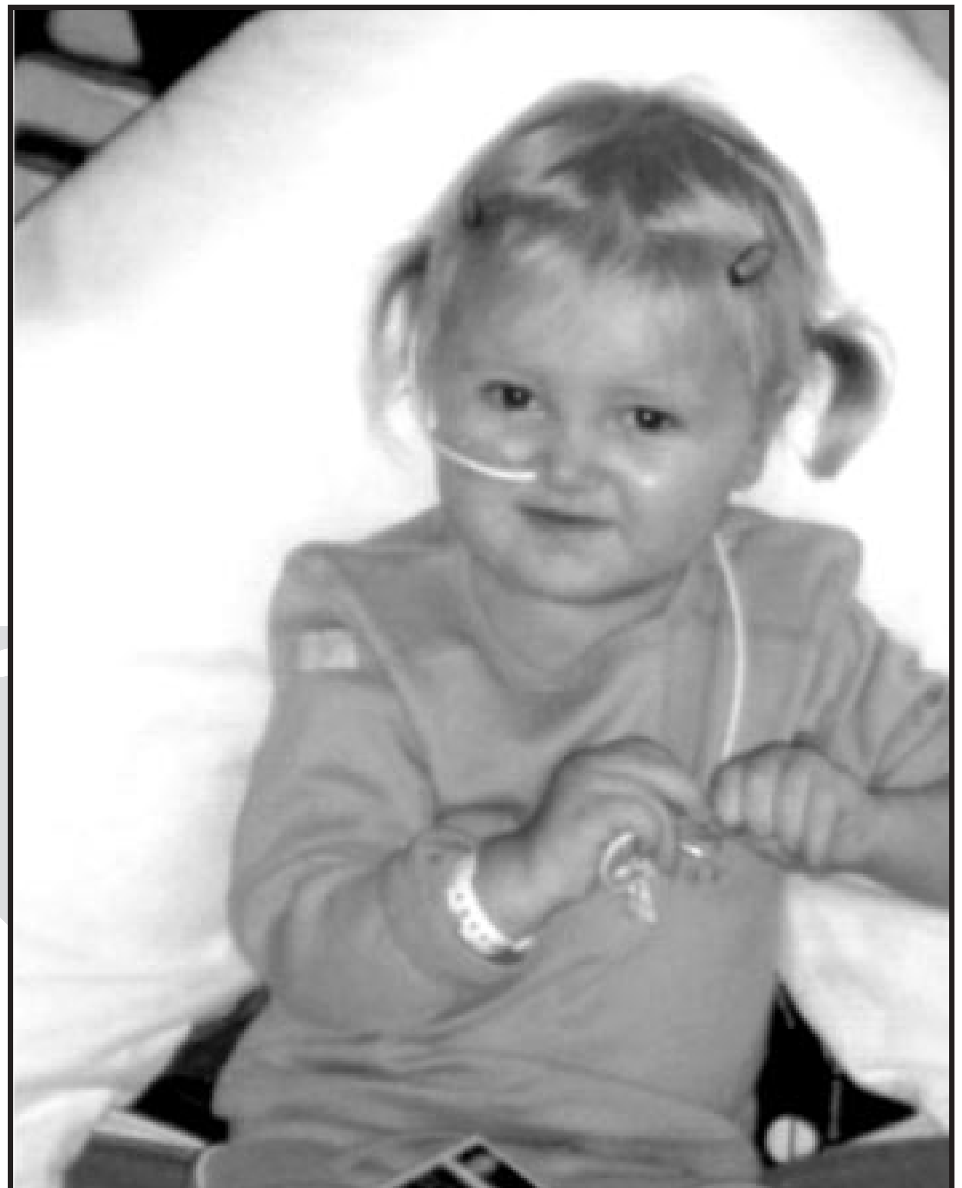


# HeartLine

Issue 60 Autumn 2003



## Ebony smiles

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# From the Editor

*Autumn 2003*

Wouldn't it be nice if our GP had all the help needed to treat our child, however complicated the heart problem, however pulseless the left wrist, however deoxygenated the blood? There are GPs who can understand congenital heart conditions, there are community pharmacists who will hand over syringes of the size you want, there may even be casualty departments prepared for a child's SVT .... But there again many of us have to manage without such understanding.

Many HeartLine members contributed to the *Now you're out!* research, which showed how badly many families need support local to their homes – especially those who live some way from their paediatric cardiac unit – see page 11. As a GP said after hearing about the research – GPs need better information from the hospitals: not just what treatment the child has had, but what this means in terms of flu vaccination, or antibiotic cover for example.

Hazel Greig-Midlane

HeartLine

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**Please send your pictures and stories for Issue 61 Winter 2003/04**

**by email:**

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HeartLine Office details appear on page 10.

**Front cover:**

Ebony Fisher

# A FATHER'S STORY – Part 2

*In the Summer issue of the magazine Michael Spencer wrote of the first five months of his daughter Chantalle's life. Here he tells about having her at home:*

### Home

Chantalle was still very weak, and feeding primarily through her NG tube. Our community nurse visited soon after we got home, and arranged for a physiotherapist to come. Chantalle was five months old yet could not hold her head up, roll over etc. Our Community nurses certainly were/are a great help. Chantalle would regularly pull her NG tube out – and until we got used to putting it back down, they would come within 30 minutes of us calling. The physiotherapist referred us to the Camden Development team (CDT) – a group including our community nurse, a physiotherapist, dieticians, speech therapist and paediatrician. Going forward the paediatrician there would co-ordinate Chantalle's care – and it was through the CDT that we got a special chair for Chantalle – one that correctly supported her, and enabled her to sit. It was the CDT that carried out her review at nine months -a very through assessment of Chantalle's development. At nine months, her gross motor skills were at about a five month olds level.

### Loathed the bottle

We kept her on her Monogen (prescription powder food) feeds until May. At that time, I had five weeks of gardening leave so Seiko took our son back to Japan and I looked after Chantalle and Hana (our oldest). I had the responsibility of gradually moving Chantalle from her Monogen to SMA. Despite the gradual change, Chantalle did not tolerate the SMA. I was shocked to see what I thought was blood in her nappy, and the final straw came when I saw blood in her vomit. She also loathed the bottle. Up until that time she tolerated 30-40 ml a feed from the bottle – from when I started the SMA, she cried at the sight of the bottle. Her temperature spiked the day after Seiko returned, so after calling GOSH, the recommended I take her in for few nights for observation.

We went back to the Monogen feeds but from then on, her vomiting got worse – with at least two feeds a day lost. Our physiotherapist suggested we thought about a gastrostomy – it would free up her face plus may help the vomiting. With that in mind, and her difficulty feeding, we asked our paediatrician to refer us to a Gastro Specialist. Her gastrostomy was planned for the next week, when he would also take a number of biopsies from her stomach lining and also test for reflux.

### Failure, success and investigations

We took her into the Portland on Saturday morning, and she went down to surgery at around 2 pm. We were assured it would only take 45 minutes. After an hour and a half she had still not returned, and we were getting worried. Another half and hour, and us badgering the nurse, we were allowed down to the recovery room. She was not looking good – on oxygen, pale and sweaty. They had failed to insert the gastrostomy. The specialist could not see the endoscope properly. With the liver blocking ? … perhaps her stomach was located on the other side of her body? ... in any case, she had to stay in hospital for two days. It looked to us as if she had had heart failure while they were trying to carry out the gastrostomy. It was decided to ask a surgeon from GOSH to carry out the procedure two weeks later. We were worried but it went smoothly.

During this time, she also visited Professor Muntoni's team at the Hammersmith, who, despite extensive tests, could find no explanation for Chantalle's hypotonia. The investigations are ongoing.

### Bronchiolitis

After Chantalle's discharge from GOSH in the March until that following Autumn, she was never really ill. We had the odd complication with the feeding etc but the situation never became that serious. We were becoming quite optimistic, with Chantalle putting on weight and getting stronger. We were feeling confident enough to ask the doctors if they thought that perhaps next year she could fly and maybe make it back to Japan. 'If she makes it through the winter, and her condition continues to improve, it may be possible…'. At the time the 'if she makes it through winter' condition barely registered – of course she would get through winter!

Her first brush with what seemed to be bronchiolitis was in October. We had noticed she was having difficulty breathing, so decided to take her into our local hospital. We took her into A&E. As usual, the registrars had difficulty finding a vein for a cannula. She was kept in for four nights, on oxygen, and made a reasonably quick recovery. She did not test positive for RSV. She didn't on her second episode either- in the November, immediately following her first flu jab. On that occasion, the doctors let my wife bring her home after a few hours, on the condition that if Chantalle's condition did deteriorate, she would bring her straight back in.

### Nervous doctor

It was on that occasion that the registrar asked why we were bringing Chantalle into the local – suggesting she should be in GOSH. It was the same one we saw in October, and we felt that he was quite nervous with Chantalle. I suppose it is quite understandable – with little experience of cardiac patients, and Chantalle's other conditions, she is a challenge.

The third episode started on December 17th. It followed a similar pattern to the previous one – the day after her flu jab, difficulty breathing, but on this occasion she had a bad cough and was quite lifeless. Despite her 'floppiness' she was always on the move, turning over, rolling around, trying to crawl etc. On that day she couldn't do anything, and the community nurse came to see her a few times. We decided to take her into the A&E at the Royal Free, and went to the same place as before. This time, though, Chantalle's condition noticeably deteriorated over a thirty minute period. Her blood gases were poor, and her heart rate was stuck in the 170s even when she wasn't crying. She became very pale.

Thankfully one of the doctors realised the seriousness of her condition, and the decision was taken to transfer her to ICU. It was also decided to intubate her – she was fighting the oxygen mask, and her blood gases continued to deteriorate. Our local hospital does not have a PICU.

Meanwhile, the search for an ICU bed was on. The story we got then that CICU at GOSH were reluctant to admit because she was seen as primarily a respiratory case. In any case, they had no beds. One was located at King's College hospital in

South London, and after many hours waiting, the CATS team arrived. By the time we arrived at King's, Chantalle was there and being settled down. Her condition was reasonably stable. The next day it was decided to try and reduce the paralysing drug with the aim of reducing her ventilator dependency. The CVP was in the 40s, and so she was started on antibiotics. Her liver and kidney functions were abnormal. Her urine showed high levels of ketones, and showed one of the liver enzymes to be at abnormally high levels – the AST, indicative of a viral infection. That day she did not respond well to coming off the paralysing drug. Her breathing action was not normal, so it was decided to keep her ventilated, just to support her through this viral infection.

The person in charge of the ICU had worked on CICU – we had a meeting with him that afternoon. He was very plain speaking, which we appreciated, although the message was stark. He told us he thought she had dilated cardiomyopathy or myocarditis. Both very serious, with a risk that she would die. He emphasised that he did think she should be at GOSH, since they knew her. He couldn't be sure of the state of her heart until they got the one cardiologist to do them (and us) a favour and come and have a look. With Kings specialising in the liver, the cardiologist came up from the neonates department – he would probably come the next day.

Chantalle was started on full feeds – until they realised the fluid coming out of her nose was the milk. They then realised the seriousness of her reflux, and reduced the feeds. There were two nurses on the ward who had extensive experience on CICU at GOSH. One of them remembered Chantalle, and came over to chat to us and the nurse looking after her. With Chantalle's pulmonary problems she said it was wise to keep the blood pressure on the high side and to ensure she was 'peeing' properly. They had doubled her dose of diuretics to try and get rid of some of the build up of fluid, and they inserted a catheter so they could properly monitor her urine output.

### Go home … come back

Seiko had got a room at the hospital, and with Chantalle having had a reasonably stable day I decided to go home that night. By the time I arrived home, I had a message to return directly to the hospital – Chantalle's condition had deteriorated rapidly. Her sats had dropped to 20%, mean blood pressure to about 20 and heart rate to 60. They suspected a blocked ventilation tube. The nurse had carried out CPR. They decided to move the ventilation tube to her nose from her mouth. By the time I arrived at the hospital, she was stable on 100% oxygen but a rate of about 180, and blood pressure in the 40s. The dopamine dose had been increased by 1/3. After a while Seiko went to bed while I sat with Chantalle over night. There was one stage where Chantalle dropped her sats and blood pressure very quickly, and her heart rate jumped to 200+. Without any aid, she made a recovery. Sabine mentioned that they had not found a blockage in the tube earlier, and with a new tube in, it was likely that what Chantalle was doing was 'shunting'. There are two types – one in the heart and one in the lungs. In the lungs it is between the bronchioli and the arteries – and it was likely that this was what was happening in Chantalle.

Chantalle was on more morphine – with pulmonary hypertension cases it is important to sedate the patient. She also had to have supplements of calcium and potassium since her diuretics were draining these away. Her feeding was stopped, and she was put on a drip. The cardiologist reported that the output from her heart was only 18%. It was likely the virus had got into her heart muscle.

### Very serious

At 5 am, Seiko and I switched, but by 5.30 Seiko came to get me. Chantalle's condition was very serious. She needed suction to clear secretions in her ventilator, but she wasn't recovering her sats even after this and with constant 'bagging'. Again, the numbers took a dive and for what seemed an eternity all the monitors were a flat line. Sabine and the duty doctor carried out CPR again – adrenaline, atropine and heart massage. There were still no signals – a brief blood gas and it looked OK. Sabine's heart massage brought her blood pressure back up. The doctor turned to us after a while and asked did we realise how critical that period was. We certainly did – we thought we had lost her.

### Bringing nanny, home help and children

Chantalle made a come back again – but we weren't sure whether she would make it if she had another episode. We wanted our nanny, the children and our home help to see her. Our nanny she was staying at home with the other two children while we went through this. Our home help is more like a grandmother for our children – a very sweet Italian lady, who means so much to us. They came in the morning – our son couldn't understand why we couldn't take Chantalle home, and our daughter asked very matter of factly what each and every tube was for. She is five, and our son three.

### Transfer …. cancelled

The doctor was working hard to get Chantalle transferred to GOSH, or Barts. We were in South London now so much discussion went on about who would take her where, but in the end it was decided she would be picked up by the CATS team and taken to GOSH. They arrived in the early afternoon, and we had our initial discussions. We were so relieved. One of the Kings doctors asked my wife and me to go with him to discuss something – the transfer had been cancelled. Some other child who was in a worse state would take the bed It meant another night in King's so they decided to set up their nitric for her – and thankfully Chantalle was stable.

### Thrown away by traffic

The next day we transferred. Chantalle had a pulmonary crisis as they were changing her drugs over to the portable syringes. The ventilators used in the ambulances are not as good as those in the hospital – and Chantalle's breathing was so poor, the doctor decided to 'bag' here the whole way across London. The traffic was bad, and the ambulance driver was not certain how long it would take to get across London. The police offer no help whatsoever – they are permitted to neither escort nor clear a path for an ambulance. I was furious – the doctors had worked so hard to save Chantalle's

life, yet it could easily be thrown away by traffic. If she had another heart failure in the ambulance, they would not be able to save her. The risks were still worth taking, and she successfully arrived at GOSH. We were not allowed in to see her – she had had a pulmonary crisis as they moved her again, and she was not settling onto her new ventilator. After about an hour she was stable enough for us to see her.

### Couldn't find files

The doctors were still not sure what was wrong with her. We stayed with her and slept from about midnight. At 2.30 am the nurses ran to get us – Chantalle had had yet another pulmonary crisis. The senior intensivist was called, and yet again Chantalle was stabilised. We had a meeting with the intensivists, cardiologists etc. They relied on our file of notes for Chantalle because they could not find her files. We keep a record of every letter. They said what was so hard was there was no indication of when one of these periods would appear. Her readings would be generally stable, and all of a sudden her sats and blood pressure would drop.

### Tears

Due to Chantalle's underlying muscle condition, they thought there was a high risk of cardiomyopathy. And because of the hypotonia etc, a transplant as well as ECMO were out of the question. Chantalle had had four or five heart attacks, and they were not certain that she could get through the next one, nor indeed, what sort of state she would be in – she could have suffered brain damage. She looked in a terrible condition – bloated, pale and essentially kept alive by drugs. On the next episode of CPR, we could ask the doctors to stop after a certain time. We were absolutely devastated – should we keep going to keep her alive come what may or decide enough was enough? We were left in the room after the meeting, and held each other, both in tears.

### Weaned

Chantalle must have known, because she did not have one more episode. That is not to say it was all plain sailing – they had to change the ventilator tube since it was leaking. That and every time they suctioned, there was a doctor nearby, and extra nurses in case she deteriorated. Gradually, all the drugs were weaned and oxygen reduced. However, yet again it was difficult to wean her off the ventilator. After about four weeks it was decided that she needed a tracheostomy. Her heart was stable at this point, and they were keen to move her on.

We felt they had not given her a chance – so they tried another device She did not respond to that either, so a tracheostomy was ordered. There was a little boy next to Chantalle in CICU who also had to have one. Seiko spoke to his mother, and felt a little better about the whole process. The doctors had given us no information nor discussed the issues with us – so we refused to sign consent until they did. We were assured of plenty of support at home, with nurses around at any time.

### Who will provide medicine?

Chantalle transferred to DJW, where we completed our training of suctioning and changing the tube and tapes. We returned home after a few weeks at our local hospital while all the equipment was organised. We also had to organise the Sildenafil for when she was at home. The GP did not want to prescribe it because it is unlicensed, our local hospital thought it was GOSH's responsibility but GOSH assured us that our GP would prescribe. It was a nightmare trying to get someone to provide us with the medicine – finally our local hospital said they would provide it.

### Never been more tired

As for all the nursing support – there are two nurses that cover the whole area of North Camden. We could have two three hour slots. With all the equipment in the lounge, we decided to sleep in there on a futon we made every night. We did not have a sats monitor – they assured us we would hear when the 'trachie tube' needed suctioning. Chantalle had a lot of secretions. During the night one of us would be awake once an hour, and during the day it was every twenty minutes at least. We had never been more tired, we really looked forward to Spring, when she was due to have it removed. We had one infection during this time – she developed Strep A in her lungs, which responded to antibiotics.

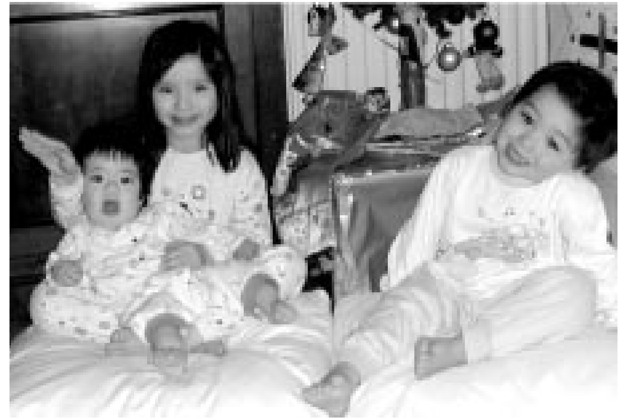
The ENT team carried out the procedure, but it was done while Chantalle was under the cardiologists. This was the problem when it came to decannulation. The ENT ward was extremely busy – we were put on a waiting list but low priority. Our intensivist did not know when the decannulation would take place. It was extremely stressful – we felt that Chantalle didn't really need the tracheostomy once the threat of viruses had receded. Seiko could not leave the house, and we were not getting much sleep. Chantalle was not gaining any weight because the tracheostomy made her reflux worse – every time she rolled over the tube was forced onto her throat, and she was not strong to lift her head up all the time. We had one episode where she turned blue on us and we had to call 999, but she was OK after a night on oxygen. We had lots of problems with old portable suction pumps where the battery would run out too quickly. Finally the decannulation occurred on May 23 2003 – she had had it for close to four months.

### Trial by decannulation

The 'trial by decannulation' was also a very stressful time. We had to go onto DJW because there were no beds on the ENT ward. Chantalle was admitted on the Saturday. We had initially been told that they would proceed slowly and cautiously – but once in there, we were told they would stick by the schedule used for every patient. They reduced the size of the tube, and the next day blocked it off totally – so Chantalle had to breathe around the tube. She had a rough night, having to be woken up to breathe on a few occasions. The doctors were keen to stop the trial, and send us home with Chantalle with the tracheostomy still in place. Seiko threatened to take Chantalle to another hospital, and we persuaded them to give her one more chance. The ENT registrar assured them that he thought the stoma would still be big enough to get some form of tube down if required. The doctor who had virtually saved Chantalle's life by bagging her from King's was on duty at the time – and was

very supportive.

Chantalle got through the next night – but it was noticed that she dropped her Sats fairly regularly during the night. It was raised on the round, but a sleep study would be arranged so sometime in the next four months. They wanted to observe Chantalle for a few more days. That afternoon, during her afternoon nap, she dropped her sats right in front of one of the doctors. She hit 60%, but recovered. It was enough to persuade him that she needed a sleep study before coming home, and miraculously arranged one for that night. The results were not good – she dropped her sats on at least twenty occasioned during the night (to below 90%) and her tidal CO2 levels were high too. It would indicate that her breathing is too shallow during sleep. Sleep apnoea is quite a common condition, but it was decided that she should be sent home with oxygen to use when she is asleep. We also have to consider the procedure where the top of the stomach is tied to reduce the risk of reflux while she is asleep, which may be causing this apnoea.



**Enjoying the summer ….**

That is the story so far. Chantalle is currently doing very well. She is 19 months old and still only 7 kg. She can roll around, but can not crawl or sit unaided for any length of time. The tracheostomy has meant she has not developed any speech skills, but at least she can now make a noise! We are seeing her cardiologist every three months to monitor her – she is growing, but her pulmonary valve is not. The pressures are not critical yet. She has successfully been weaned off sildenafil, but her anti reflux drugs (three) and diuretics (two) are essential. The summer is great with no viruses around, and she is making progress. We decided to buy her a special pushchair because it was such a long waiting list – six months at least, and we want her to get out and enjoy the summer while we can.

**Terms used:**

***RSV:*** respiratory syncytial virus which can lead to bronchiolitis in susceptible children

***CATS team***

***Ketones:*** (beta-hydroxybutyric acid, acetoacetic acid, and acetone) are the end-product of rapid or excessive fatty acid breakdown

***AST:***

***dilated cardiomyopathy or myocarditis:***

***CPR:*** Cardiopulmonary resuscitation

***pulmonary hypertension***

***ECMO:*** Extra Corporeal Membrane Oxygenation

***Sildenafil:***

***Unlicensed:***

***Strep A:***

***ENT:*** Ear Nose and throat

***tidal CO2:***

***apnoea*** lack of breathing

***gastrostomy:*** a hole made into the stomach so that a child can be fed directly into the stomach.

***Monogen*** powder prescription food

***Chylothorax*** lymph glands leaking into chest cavity

***pleural infusion:***

***oliguria:*** a very low amount of unrine produced

***hyperventilated:*** given a lot of breathing support

***pulmonary hypertension:*** high pressure in the lungs

***a tracheostomy:*** a hole made into the windpipe to enable breathing

# VISIT TO LEEDS

Leeds General Infirmary has a large Paediatric Cardiac Unit. The cardiac liaison nurses are Wilma Dickson, for the younger children, and Jo Quirk, who looks after the older ones.

There is a unit on the ward for older children. Michelle, 16, was enjoying her room with her own TV, computer, CD player, couch, very comfortable bed and all ensuite.

Jo showed me around the outpatient area for older patients, with suitable GUCH display and material. Then I met Ebony with Dad and Mum, Mark and Susan. Ebony was born with Fallot's Tetralogy – but noone would know from how active she was, and there had been no problems feeding her. She was in for the final repair. When I wrote to ask how the surgery had gone, I had an article back and some pix taken by Mark – one of which features on this issue's front cover.

*Jo Quirk, Cardiac Liaison Nurse*

# EBONY

*Ebony was expecting surgery the following day for Tetralogy of Fallots when I met her on the ward at Leeds. I got back in touch to ask if I could use pictures of Ebony in the magazine and Mark and Sue sent me the following email:*

***Thank you for the pictures of Ebony taken in August when you visited Leeds General Infirmary.***

That day we had the heart scan done to see if the baby that Sue is carrying has any heart problems: thankfully we've had the all clear as they can't find any major defect- big relief.

### Sent home

Ebony had her pre-op test done that day, but at 1am Ward 10 rang us in the Parent Accommodation to say that the operation had been cancelled as the surgeon was still in theatre. This was the second occasion it had been cancelled. They sent us home and said they would try and do the operation asap.

We received a letter saying they wanted Ebony to go back into hospital on Friday 29 August to repeat her preop tests, then for us to go home and return on Sunday 31 August ready for surgery on the 1st September.

### Very long hours

Ebony's operation went ahead. She was in theatre a lot longer than they had expected as they discovered another hole and the narrowing in her artery was worse than they had thought. She was in theatre for nine very long hours.

After her surgery she did well. She had a few problems in CCICU with her blood gasses and was critical for forty-eight hours, but she was back on Ward 10 four days post op. She still had both chest drains in but the doctors explained that after the surgery she had undergone there would be a lot of fluid build-up. She was very sleepy for the first week after her surgery which the doctors were concerned about even though she was getting back to her normal self.

### Smile on her face

She would push her drains up and down the ward with a big smile on her face. The nursing staff said that it was rare to see a two year old trying to run to the toy room pushing her drains along without a care in the world.

### Diet

The drains had not slowed down by this time so she was prescribed a course of injections that they rarely used. Also the fluid in the drains had started to become cloudy which when tests were done showed she had chylothorax, and was put on a low fat diet of two grams a day. The diet was so hard for Ebony as it meant none of the nice food that she was used to. By this time Ebony was three weeks post op and was starting to become fed up as the drains were holding her back.

On Saturday 20 September Ebony started with a high temp and high resp rate, and was not her normal self. Also no fluid had drained from one of the drains the day before so they did an x-ray which showed the drain was blocked and that the fluid was building up on her lungs.

### Collapse

Finally the surgeon was available around about three pm and Ebony was taken down to CCICU for the drains to be removed and new ones inserted. They told us it should only take an hour and she would return back to Ward 10 shortly afterward, but nearly three hours later they came and told us that when they put the new drains in and removed her from the ventilator she had collapsed and was showing signs of infection. At first they did not know what they were treating so they put up several antibiotics to cover every part if her body.

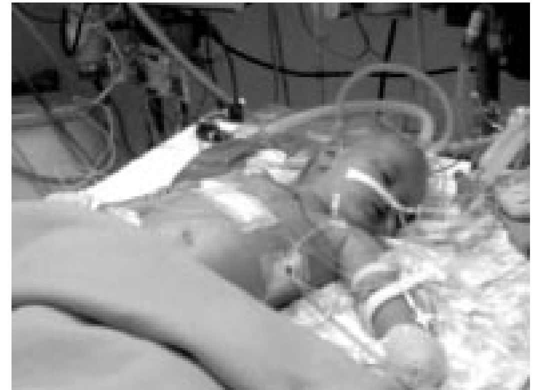
### Unfair

When we went to see her it was heart breaking. She was back on the ventilator and wired up to the heart monitors and all the drips in her, she looked ten times worse than she did after the operation. It was so unfair that she had got so far after surgery and then this had happened. They told us that they had brought her down just in time – any later and she would have collapsed up on the ward.

### Worse

They said that she was critically ill and that we should not expect any change in the next seventy-two hours or more. As the next few hours passed she became worse – she had become purple and was swelling up and they started treating her for meningitis. But they were not sure if it was that – they just knew it was a serious infection, but would not find out until the results came back.

That was the worst part -our little girl's life was in their hands and they did not



know what to do – it was very scary. Thankfully she got through the night and later that day the results came back saying there was an infection where her left drain had once been so now they could treat the infection directly – at last some good news.

### Set backs

She was on ten different drugs at one point all being pumped into her. They had even started talking about kidney dialysis as her kidneys were starting to fail. After a few days she started to get better and a week later she was taken off the ventilator and taken back to Ward 10 (something everyone thought would never happen).

So much had happened on CCICU – she got a blood clot in her right leg and her drains had not slowed up, so they were talking about taking her back to theatre – all more set backs for her but she pulled through. They said the infection had been building up for some time. Normally when they leave the drains in as long as she had had them, the body starts to reject them, but up until now she had showed no signs and had just carried on.

Back on the ward she was in HDU for a week, then moved on to the ordinary ward. She still had her chest drains and neck line to give her the different antibiotics she was taking. She had changed so much, no longer the happy-go-lucky smiling little girl, but it was wonderful that she was still with us after all she had been through.

After she came out of HDU she was allowed to have food at long last but it was still on the low fat diet. She had to have twenty-four hour feeds through her neck line but in the end she had to have an ng tube down to feed her.

**Leak**

So much had happened it is hard to write it all down in order as it is still all sinking in – what we have had to go through. They did an echo and found that the patch they put over the hole was starting to leak. But the heart had started to settle down at last – after surgery her right ventricle was very stiff and there was too much pressure – so it was a bit of good and bad news. They said they wanted to take her down for a catheter, but now would be the wrong time. With her being so seriously ill they wanted to leave her till she was much stronger.

**Drain out**

Over the next few days she started to eat more and get ever stronger. An x-ray showed their was still more fluid on her lungs, but they still decided to remove the drain as they could do more damage than good, and hopefully her body would start to absorb the fluid. So at long last her drain came out six and a half weeks after surgery, and her neck line was removed. After that they were happy for her to go home as she had been through so much and would recover better there.

**Home, but …**

So after seven very long weeks we were able to return home. When that day arrived we were on cloud nine. We've only been home one and a half weeks and she is doing well. We have got to take her to LG I on Wednesday 29 October for a check up as she still has fluid on her lungs, and with her being so poorly with the infection her liver is enlarged . They said they would probably want her in in December for a catheter which we do not want to think about as Christmas is nearly on us and the birth not so long away. We were hoping this operation would be the end of it for us. We were wrong – there's still a long way to go but we are so grateful and lucky to still have her We can't believe a two year old could be so strong. She's our little fighter.

**Terms used**

***Tetralogy of Fallots:*** there are at least four defects with this problem – the right ventricle is thick, there is a hole between the ventricles, the aorta is directly above this hole, the outlet around the pulmonary valve is narrow. As a result of these problems, some deoxygenated blood is pumped directly into the aorta.

***CCICU:*** Children's Cardiac Intensive Care Unit

***Chylothorax:*** the thoracic duct is sometimes damaged during surgery and can leak lymph fluid into the chest.

***high resp rate:*** breathing fast

***HDU:*** High Dependency Unit

***ng tube:*** nasogastric tube for feeding via the nose directly into the stomach

***echo:*** short for echocardiogram – an ultrasound scan

***right ventricle:*** the ventricle which pumps deoxygenated blood to the lungs throught the pulmonary valve.

***Catheter:*** a long fine tube which is threaded through a vein and into heart – here it can test pressures, or be used to widen valves and block some kinds of hole.

**September 27th - children enjoying the Thames boat trip for all Area Contacts and Core Support Group as a thank you for all their hard work for HeartLine at the start of our 25th year.**

# MEMBERSHIP FORM

We welcome all friends and families with children with heart disorders, and professionals with an interest, into HeartLine Association. You need to return this form to the Office Address to become a member, or update your or your child's details – such as changes of address or your child undergoing treatment.

Your details will be kept on a database used by the Office.

Your details will not be given to anyone without your permission.

**Please describe your relationship to the child, e.g. parent, grandparent, etc.** ..........................................................

Name.................................................................................. Partner's Name ..............................................................

Address ..........................................................................................................................................................

..........................................................................................................................................................

Telephone Number .......................................................... Email Address ..............................................................

Heart Child's Name .......................................................... Date of Birth ..............................................................

Name of Heart Condition ..........................................................................................................................

If the child has other health problems, please give broad details ..........................................................................

If the child has been treated for the Heart Condition, please give the name of the hospital and details ...........................

..........................................................................................................................................................

**Other children in your family**

.................................................................................. Date of Birth ..............................................................

.................................................................................. Date of Birth ..............................................................

How did you hear about HeartLine? ..........................................................................................................

- Please pass my details to my local HeartLine Area Contact yes / no
- I would like contact with local families yes / no
- I would like contact with families and children with a similar condition yes / no
- I am willing to support other families yes / no
- *Please delete as appropriate*

**HeartLine does not charge a membership fee but relies heavily on voluntary donations for services to families. We are grateful for any support you can give us.**

*"I would like to help HeartLine. Please find enclosed donation of* ..........................................................................

If you are a tax payer and agree to HeartLine reclaiming the tax please complete and sign the following:

I want HeartLine Association to reclaim tax on:

- The enclosed donation of £...................
- The donation of £................... which I made on ...................................... (date)
- All donations I make from the date of this declaration until I notify you otherwise.
- *(Delete as applicable)*

I understand that I must pay an amount of income tax or capital gains at least equal to the tax HeartLine reclaims on my donation in the relevant year.

Signed .................................................................................. Dated ..............................................................

*Please return completed form to:* **HeartLine Association, Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey GU15 3HH**

# HEARTLINE OFFICE SERVICES

The Camberley office is open Monday through Friday, between 10am and 4pm. Messages can be left outside of office hours, and will be dealt with as soon as possible on the following working day.

**Tel: 01276 707636 Fax: 01276 707642**

**E-mail: heartline@easynet.co.uk**

**Web Site: http://www.heartline.org.uk**

**HeartLine Association, Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey GU15 3HH**
Administrator: Pamela Lawrence
Fundraising Officer: Neville Terry

## LEAFLETS AVAILABLE

Dental Care for Children with Heart Problems
Feeding for Children with Heart Problems
Respite Care

## FOR SALE

| Item | Price |
|---|---|
| Pin Badges | £1.00 |
| HeartLine 20th Birthday T-shirts<br>Age 3-4, Age 7-8 | £5.00 |
| New Updated 'Heart Children' Book | £5.00 plus £1.00 (p&p) |

## BOOKS TO BORROW

Pregnancy Loss • Choosing for Children • Parent's Consent • When a Baby Dies
Operation Fix-It • Rosie Goes Red, Violet Goes Blue

## VIDEOS TO BORROW

Children and Heart Disease • Children and Catheterisation
Children in Surgery & Intensive Care • First Sight
Compilation from Children's Hospital, Ablation, Pacemaker, Closing ASD with Device
Living with Warfarin • When Our Baby Died

The Office also has a large number of leaflets about children in hospital, their rights, medicines, pain, feeding, education and information about a number of different kinds of heart defects.

**ORDER FORM** – please send to HeartLine Association, Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey GU15 3HH

Name ..........................................................................

Address ..........................................................................

Postcode.......................................Daytime Tel. No. ...................................

Item or description ..............................Quantity..............................Price..........................

I enclose a total payment of £....................................plus a donation of £ ..........................

A contribution towards postage would be much appreciated, and would help us to help more families.

Thank you.

# MINIATURE STEAM TRAIN RIDES

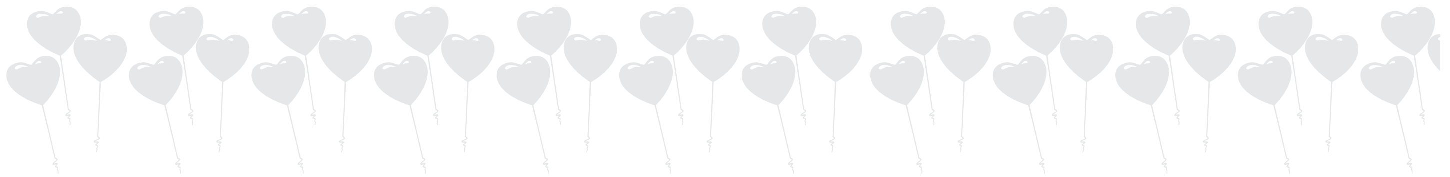
***Alison Keen, Essex Area Contact, writes:*** Having just taken over from Daphne I was more than a little nervous about organising my first 'event' for Essex members. But I needn't have worried. The 4th of October arrived dry and bright, albeit a bit on the chilly side. Over 20 families came and I would also like to thank those who couldn't attend for letting me know.

It was lovely to see all the children's happy faces as they steamed around the grounds and the mums and dads looked to be enjoying themselves too!

Many thanks to everyone who came for their generous donations towards food and raffle prizes. Not only did we cover our costs but there is a little leftover towards next time! Thank you also to Lisa Foster for my lovely flowers, and special thanks go to my husband, Andrew, for doing such a sterling job in the kitchen making tea and coffee! And huge thanks to CSME for giving up their Saturday to give us all such a lovely time.

I'm sorry I didn't have a chance to chat to everyone – I'll try harder next time.

A few members have asked me about coffee mornings. I haven't arranged anything yet, but if interested members could let me know I'll see if I can arrange a mutually convenient venue.



# DISCHARGE FROM PAEDIATRIC CARDIAC UNIT: a survey of families

Taking your new family member home at last......if your new baby was rushed into hospital with a heart problem, this is the occasion you have been awaiting for several months.

Or maybe your older child had been on the list for surgery – weeks, months or even years of waiting, followed by arrangements for while you are in, tests, surgery, intensive care, and recovery.

So the moment has come. You are being discharged. Packing clothes, cards and presents into a bag only big enough for the clothes, you just have to wait to speak to the nurse to get the medication, and then you are off. You wait patiently (or not) and finally nurse with paper bag and other pieces of paper arrives.

You are given the medicines, told what to do with them, follow-up appointment date for outpatients perhaps at your local hospital, to look out for inflammation on your child's scar, a telephone number to contact, a letter that has been sent to your GP, maybe feeding instructions. You may have a few questions – can he sleep on his front, can she go on holiday to France, where is a staff member you want to thank or to say goodbye to.

So now you are home – the medicines go into the fridge – or not. Are you sure where they should be kept? Someone has helpfully run a bath for child to play with new water-toy – should you keep the chest dry, or was it just clean? Your child won't eat and won't settle, a slight fever maybe? Should you speak to the hospital, your GP, health visitor, community nurse or just go straight to A&E?

While the heart services for children were being reviewed, many parents told the Children's Heart Federation (CHF) that they felt lost and alone after their children came out of hospital. They reported difficulty with feeding, getting medication, unhelpful community health services, lack of knowledge and understanding at their local hospitals. They feared that they had insufficient information to be responsible for their child's care.

To see what kind of problems parents have, and to suggest ways in which they should be remedied, Claire Stevens of CHF carried out a survey of parents whose child had recently come out of the Paediatric Cardiac Unit (PCU) after treatment for a heart condition:
*Current Perceptions of Families on Services After Leaving the Paediatric Cardiac Unit. August 2003*

What she found broadly is that practice is different depending on which children's heart hospital you attend, and that the hospitals are often seen to be good at one thing, and really inadequate at another.

### Recommendations

The two broad recommendations of this report are:

- Full information tailored to the family's needs, (written and verbal) is provided on caring for each child before discharge from the PCU.
- Specialised support is made available at community level.

If you would like to read the full report it can be accessed from:
www.childrens-heart-fed.org.uk
A shorter booklet is on the website or can be sent free from CHF by calling 0808 808 5000, or emailing chf@dircon.co.uk

# UPDATE – LEWIS

*October 2003*

***Melanie Osten writes:***

I thought I'd just write a quick update to let you know how things have been going with Lewis lately. Lewis is now 3 years and 6 months old. It's been a long time since my last update – and I don't really know where to begin!

Our main major development came in the form of a trip to London to the Nuffield Hospital for Hearing and Speech back in March when Lewis was 2 and 10 months. He had a really thorough assessment and was finally diagnosed with severe verbal dyspraxia and severe oro-motor dyspraxia. Children with verbal dyspraxia have difficulty in making and co-ordinating the precise movements required for the production of clear speech, and yet there is no evidence of damage to nerves or muscles. They have difficulty in producing individual speech sounds and in sequencing sounds together in words. It came as such a relief to finally have a proper diagnosis and something definite to work on.

Since that diagnosis, Lewis has been in weekly speech therapy. Progress is painfully slow and it is so very frustrating to watch him try to talk. He tries so desperately hard to tell us his stories – the mouth moves and the words just don't follow. He has a lot of behaviour issues – mainly due to the frustration.

He goes back to the Nuffield on November 6th.

The diagnosis led to the LEA finally agreeing to assess him for a Statement of Special Educational Need. After many months of specialist teachers, paediatricians and educational psychologists, Lewis was finally issued with a proposed statement in August. The statement became final at the end of September.

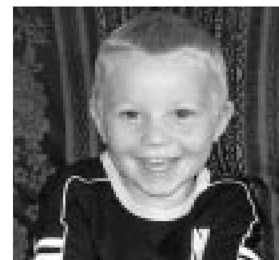
We recently had the results from Lewis's FISH test for DiGeorge. It was negative – I was so pleased! His paediatrician had decided it worth testing as Lewis presents with about twenty of the signs for this syndrome.

He still has a lot of trouble with his ears – gets lots of ear infections. We are about to be referred to the ENT department as our GP feels grommets might be an advantage to try and help prevent the infections. Through the summer, Lewis's chest has been pretty good (touch wood!). But since the autumn weather kicked in he's had 2 chest infections, two ear infections and tonsilitis!

He has recently had his immune system re-checked and everything stands the same – still low. Our GP has actually advised us not to bother giving Lewis that new Hib booster – as he won't respond to it anyway! (He didn't respond to his last 2 Hib jabs)

Lewis has also been suffering a fair bit with reflux – and he's now on Gaviscon four times a day to help with this. The GP said it is probably caused by a weak diaphragm since his pulmonary veins originally went through it before the repair [for Total Anomalous Pulmonary Venous Connection].

Lewis still has his leg 'problem'. It still 'appears' longer and is most definitely bigger. One leg actually measures a whole inch bigger around the thigh. He also seems to have very mobile leg joins. He sits in a 'W' position, and when he runs he looks as though his legs are 'out of control'.



Well – I think that about covers it for now – on 11 September, Lewis started Nursery – I really can't believe that my little baby has grown up so quickly!

Before I go – I'd just like to say a BIG Thank you to Alison Keen. You have been such a huge help – both in getting the verbal dyspraxia diagnosis and through the statementing process. Everyone should have a friend like you. Thank you.

**Terms used:**

***Verbal dyspraxia:*** difficulties in combining elements of speech

***Severe oro-motor dyspraxia:*** problems with controlling mouth and throat movements to produce speech

***FISH:*** stands for Florescence in situ hybridisation: a way of identifying gene microdeletions such as 22q11.2

***DiGeorge:*** Syndrome caused by deletion of part of gene: 22q11.2

# SURVIVING A NASO-GASTRIC TUBE

*Liz Collins writes on a huge issue for many HeartLine members*

I am writing this article to offer support to those of you who face the nightmare of feeding problems associated with heart babies. Our daughter, Emma, was born eight and a half years ago with Tetralogy of Fallot. Obviously we experienced many of the difficulties that readers of this magazine know and share. There was a great deal of information about her condition and congenital heart defects in general. However, what we were not adequately prepared for was the problem that consumed our lives and seemed to have no solution: Feeding difficulties.

**Refused**

Emma refused to eat. Avenues we tried included breastfeeding, bottle-feeding, spoon-feeding, drip-feeding with an eyedropper, syringing food into her mouth, and the results were always the same. Complete disaster. The emotional trauma that we endured was exacerbated by the most basic primitive urge to feed and care for one's young. Emma would have none of it. The only solution that was successful was Naso-Gastric (NG) or tube feeding, which we endured for seven months.

The day her snorkel came out for good was not celebrated, but approached with a sense of disbelief and terror that the dream would not last. Fortunately it did, but here is our story in the hope that those of you experiencing the same issue can take some comfort that it can all get better.

**No guidance**

After her first surgery at the Brompton we were told that we would be able to go home as soon as Emma was feeding adequately. That quickly changed when a senior cardiologist declared that it was ridiculous for a child to be taking up a bed at a specialist heart unit simply because she was not feeding. Time to move…so back to her birth hospital we went. Finally they too decided that she should go home as she had now recovered to her original birth weight (4lbs). Off we went, with no guidance as to what we should do next.

**Failure to thrive**

One week later we were readmitted: Failure to Thrive. Not surprising as every mealtime was a screaming match of Emma refusing to open her mouth and us trying to force a teat into her mouth. As you can imagine, the idyllic picture of a mum breastfeeding quietly was very far from reality. The saviour from my perspective was a phenomenal husband who persevered when even I felt like giving up. He had some incredible schemes to get her to feed, but more about that later.

**Reinserted**

At this point the dreaded NG tube was reinserted and we were told that it would be there simply to get her over the slight problem and then all would be well. Someone forgot to tell Emma that. Some weeks later, the paediatrician removed the tube with the famous words, ' No child will deliberately starve themselves. Leave the tube out and when she is hungry enough she will eat.' Again, no one told Emma. After one week the said doctor was so shocked by her weight loss and general ill health that back went the tube. We were devastated.

**Tricks**

Nonetheless, we accepted our lot in life, and my

husband embarked on the most ingenious journey of dealing with the extra equipment in our lives. Firstly he learned to insert the tube himself. He usually had far more success than the medical staff as he had a bag of tricks.

- First hold the tube in your hands to warm it slightly (in its packet).
- Then bend it a few times so that it turns the corners more easily.
- Apply a little olive oil to the tip to help it on its journey.
- When taping it to the baby's face, shape the sticking plaster so that there is as little space between the plaster and the nose as possible. Emma's favourite game was to put her finger into that space and whip the tube out. That favourite activity did not endear her to us, especially as she usually did it when we had company.

**Outwitted**

The insertion process was also an art form. The most effective method was to lay her across a stool with one person holding her arms down with your arms and then her head in your hands. The tube inserter then had his hands free to get it in as fast as possible without injuring her. As you might imagine, this was met with a great deal of resistance and then frustrated screaming when she realised that she had been outwitted. Even at that young age, we knew that we had a very determined person in our house.

We also always changed a tube at least once a week (if we had been successful in keeping that finger out of the loop). Despite the most rigorous care and cleaning routine, the tube did eventually get clogged. So the above process was repeated many times. Eventually my husband was able to put the tube in on his own. I have no idea how he did this as the screaming infant was now slightly larger, and infinitely more muscular. At 6 foot and 240lbs, I think he applied intimidation!

**Test**

Some other important points about the tube. We were fastidious about following the instructions of the medical staff. ALWAYS check that the tube was in the correct position before feeding, even if you have just inserted the tube. We NEVER missed this step as it is too important not to. The test involves withdrawing a tiny amount of fluid from the tube and testing it on litmus paper to ensure that the contents were stomach acid. If the tube was not in the stomach it was likely to be in the lungs, and pouring a feed into her lungs was a chance we were never going to take. I cannot stress how important this is, and no matter how tired I was, nor how late at night, I never missed this step. It is tempting at three in the morning to do everything as quickly as possible, but please don't. Rather get someone to help or don't feed the child. A missed feed is better than an error.

**Birdies … what birdies?**

Our feeding routine went something like this: Throughout our NG period, we always tried to feed her by mouth first. We were concerned that she would lose the ability to suck, and more important, have speaking difficulties later in her life. Today she does have a lisp, but we have no way of knowing whether this is related. But she talks nineteen to the dozen, so no obvious problems. Again, we used the high calorie food supplied by our local hospital supplemented with Duocal. We stayed on a strict four hour feeding routine, which gave us some relief as the entire feeding ordeal lasted up to two hours on a bad day. Again my husband had sensational techniques to get her to suck a little. Distraction was usually the most helpful, with hilarious consequences. The most effective was to hold her facing a window, and say, "Look at the birdies". For some reason this had her sucking for about two or three minutes (enough to get about 20mls into her). Desperation drove us to employ the same technique at night with similar results. Hence we spent a great deal of time at windows looking at unseen birds. The technique was duly employed when we took her on an overnight flight to see her grandparents. At 30,000 feet we held her to the porthole and summoned the birds. Imagine the face of the elderly passenger who helpfully told my husband, "I don't think she can see anything, because it is too dark and probably too high to see any birds." We were undeterred and continued this charade. (As an aside, one loses all sense of embarrassment in dealing with a problem like this).

**Get over the guilt**

Another sanity saviour was to get help. In the beginning we believed that as first time parents we were at fault. The guilt I suffered was excruciating. I longed to breast feed for a myriad of reasons, but primarily because I really did believe that breast was best. But in the face of this opposition, it was impossible. Eventually I was told that it was far more important to nourish my child than to try and breast feed. I did express milk for a time, but this was so tortuous and coupled with hospital visits and being back at work (I am a full time career mum) that I gave up. I did find a small bottle of expressed milk at the back of the freezer some 6 months after I had given up which brought a wry smile. Eventually I did get over the guilt, but not without much anguish.

Help is available in many forms. Initially, we asked an experienced neighbour to feed Emma. She had less success than we did, which made us feel a little better about the problem. We also requested community support, and a visiting cardiac nurse arrived full of confidence about the problem. "I've fed cardiac babies for 20 years. You are just new parents, I'll solve the problem for you." After half an hour she left and we were alone again with a screaming fighting food resistant child. We had no backup help in the form of grandparents who could shoulder some of the responsibility. If you have access to such gems, take full advantage. Our friends were very helpful when visiting, as everyone volunteered to try their luck. However, this was embarrassing as Emma also suffered from reflux, so projectile vomiting was a frequent occurrence. In looking through our photo album of the time, every picture of friends feeding Emma has them draped in assorted towels to protect their clothing. (We have wonderful friends).

**Vomiting .. or no food?**

As an aside, to counter the reflux we added Gaviscon to her feeds, but this clogged the tube very quickly, so we tried to avoid that route where possible. The dilemma was whether we risked the vomiting, or not getting enough food into her because of a clogged tube. Changing the tube midway through a feed was not an option given the performance as previously described.

**Charts**

One tip we used was a psychological one rather than feeding related. Following hospital schedules, we kept feeding charts, which helped us track what went in and what came out. This entailed weighing all her nappies – dry and used. Also recording all feeds including whether she ate solids or not. While this may sound onerous, it helped in many ways. Firstly, it enabled us to keep track of what happened when, especially as we also recorded her drugs. That way there was no confusion as to whether we had administered the day's intake. Secondly, it was an excellent reference point when my husband and I swapped feeding duties. While one of us slept the other fed, and the record enabled the next on duty to understand what had transpired the previous feed. (This encouraged a great deal of sympathetic conversation on many occasions). However, the main reason the chart was so useful was that we could see at a glance how much she had really eaten that day. What may have seemed a completely hopeless day may well have been better in fact than perception.

**Spill it**

After some months these charts were used by all the medical staff. So much reliance was placed

on them, that the night staff completed our charts before their own during her many weeklong stays for failing to thrive. In summary, they were a comforting fact based analysis of what was going on with the child, and provided some clues as to what might have caused her to eat or not as the case might be. I would recommend that parents struggling with poor feeding think about this, as it does reduce the pressure of believing that your child is not taking anything. Another idea to help combat the sheer frustration is to pour 10mls of milk on to the floor (kitchen is best). That way you can gauge how a little milk travels a long way. That was comforting to me during the trials of vomiting. What seemed like an entire feed was probably only a small amount.

### Desperate times, desperate measures

Did we ever get through this? Well, after seven months the tube did come out, after Emma had diarrhoea and needed electrolytes to restore her fluids. She took 100ml of water by mouth, and so we decided that drinking was not going to be a problem thereafter, and we took the tube out. We persevered and she has been tube free every since. However, feeding was not straight forward thereafter either. Introducing solids was met with the same determined refusal to eat. To my shame, I remember smearing pureed baby food across her face in the vain hope that she might lick some off and get nutrition. I doubt that she consumed more than 1ml that way, but desperate times called for desperate measures.

### School

Once she was a toddler, we decided to enrol her at a pre-school that provided meals. We found a fabulous centre, where the principal was more than happy to take on this problem child. We reckoned that peer pressure might resolve the issue. While it made little difference to Emma, we resolved not to fuss, and monitored what she ate based on what we fed her. That way we ensured she had a balanced diet, and whatever she ate at school was a bonus. Despite our resolve not to let it bother us, feeding continued to be central to our lives. Emma just never ate. She did grow, although she was always way down on her centiles. We persevered, and she grew slowly but surely.

### A grape

We had high hopes for 'big' school. No such luck. Emma's school compelled every child to have one piece of fruit at each school dinner. Emma's solution – one grape! But very slowly we began to get her to eat more things, usually by a process of deception. At this stage, I am sure we could negotiate our way through any peace process. Emma is the master of avoidance!

### Feeding herself

One thing to note for those of you who have school aged children. We fed Emma at home by hand to try and get the essential food into her until she was at least six. This may sound extreme, but it was the only way to make sure that everything did get eaten. The downside was that Emma was way behind her peer group in learning to cut her food and generally use a knife and fork. Her principal finally spoke to us, and rather shamefully, we set about correcting the fault. Having said that, Emma did respond well and learned in record time to manipulate the instruments of torture and feed herself.

### Parent support

That we have come through more than 8 years of struggling is largely a tribute to my husband and his phenomenal skills and dedication to his daughter. She is a lucky girl to have such a caring father. For anyone out there with feeding difficulties, you are welcome to call me or (for the real expert view) my husband. I'll make sure that he talks to anyone with really difficult issues! Having had support from parents many years ago, we are very happy to talk others through this issue, especially as we found the medical profession were not able to provide real help and guidance due to probably not understanding the frustrations we endured.

### Support and information

In summary we have been through the worst nightmares with Emma, but today she is a very well girl and a real delight. As we guessed, she is very strong willed, but her eating has improved dramatically. In comparison with her peers, she still eats like a little bird, but she is making great progress. We would be more than happy to introduce you to her to understand that there really is great hope. We did not meet any older success stories, but I would have been grateful to see that one is able to get through this very trying time. Both my husband and I are available to talk to any parents with feeding issues, or even general issues relating to heart disorders – more especially Tetralogy of Fallot. Shortly after Emma's correction (aged 18 months) we transferred to the USA, and spent 5 years there. We received our follow up care at Boston Children's Hospital, and would also be very happy to share any information about treatment in the US with others.

The very best of luck to all of you faced with this issue. Remember, neither you or your child is the problem – their condition is. You are trying to cope as best you can, and ask for help. Many people will support you if you ask. We did, and it certainly made a difference. We look forward to hearing from you if you would like any more information or support.

### Terms used:

***Tetralogy of Fallot:*** a heart defect with four problems – a small right ventricle, a large vsd, an overriding aorta (takes blood directly from the right ventricle) and pulmonary stenosis – a narrow pulmonary valve.

***Nasogastric tube:*** a tube passed through the nose, down the back of the throat and into the stomach.

### Home Education

***Heather Brothers writes to HeartLine:***

Thank you for sending your book Heart Children, which we have found very helpful and informative. I first saw a copy at Bristol Children's Hospital when my new baby was first diagnosed and treated. It would have been good to have our own copy at the time and nice if there were a few copies on the ward for parents to read. Medical and nursing staff are busy and sometimes you don't know what you want or need to know! I would like to donate some of your books to the ward, so I will ask the staff regarding this when Francis has his next check-up.

My eldest daughter has never been to school (no health or other problems, it was just a choice) and I'm glad we have the option of not sending Francis to school. Bridget is very sociable and has good friends and the best thing about educating your own child is that you can tailor it to the individual. School does not suit all children, especially those with problems. Perhaps you could mention this choice in your next reprint as many parents may think they have to pay for a tutor and be unaware of their legal rights. I have met many children who have suffered for a long time because a school was not suitable and parents were uninformed.

Education Otherwise is a self-help organisation which can offer support and information to members who are practising or considering education at home. You can contact them by telephone: 0870 730 0074, or by visiting www. education-otherwise.org, or by writing to Education Otherwise, PO Box 7420, London NB9 9SG.

### Medic Alert

Does your child need a Medic Alert bracelet? This may be because he or she has fainting attacks, a family history of Hypertrophic Obstructive Cardiomyopathy, is on warfarin, has a pacemaker, or has an allergy for example.

HeartLine can cover the cost – just send your name, address and telephone number, the name of your child and the hospital he or she attends to Helen Baker at the HeartLine Office.

### Share!

Whatever you would like to say about your child's treatment is likely to be of interest to other parents. We are likely to be equally fascinated by tales of claiming DLA, statementing, diet, holidays, feeding, genetics, schools, transport and any other aspect of life with a child with a heart condition.

And as every day babies are born with parents who have only just learnt of heart defects, you don't have to be original. Everything you write will be new to someone.

Articles that appear here are put onto the HeartLine website. If you would rather they didn't, just let us know and we'll limit to the magazine.

### Message Board

What people are up to on the HeartLine message board:

● 'I have booked a room for a Christmas get together on 13th December.' Families are getting ready to celebrate Christmas

● 'spoke to my GP again yesterday and he is still saying no to the flu jab, he says he does not like giving it to children but if I

insist …' Puzzling out NHS policy on protection of children with heart defects from flu

● 'I've noticed that a few of you mention reflux is associated with heart problems –' feeding: the always popular topic.

● 'I have a 4 yr old son who has a condition called e.f.e. He had a mitral valve replacement last year and is now on warfarin' And advice on warfarin is being sought.

Join in – go to www.heartline.org.uk/messageboard

### New York! New York!

Two tickets to New York – must be worth the price of a book of raffle tickets to get a chance like this! If you didn't get HeartLine raffle tickets with this magazine, contact the Office – see page 10. The draw will be made on 20 January, and tickets need to be back by 13 January

### Website

Jonathan Bacon's mother, Pam Adlington, reminds us that you are very welcome to visit Jonathan's memorial website at www.geocities.com/johnny29po/index

**HeartLine's elder stateswomen, Tricia and Fiona, and patron Phil Rees on boat trip in September.**